Welsh Parliament
Health and Social Care Committee

Priorities for the Sixth Senedd

Share your views

Background

The Health and Social Care Committee has been set up by the Senedd to look at policy and legislation, and to hold the Welsh Government to account on specific issues. This includes the physical, mental and public health and well-being of the people of Wales, including the social care system.

During autumn 2021, the Committee will be considering its strategic approach and forward work programme. To make sure that we can take account of what you think the most important issues are, we would like you to share your views on:

1. The initial priorities for the Sixth Senedd identified by the Committee (see below).
2. What other key priorities the Committee should consider during the Sixth Senedd in relation to: health services, social care and carers, and COVID recovery.

How to share your views

To share your views, please complete this form and send it **by 16.00 on Friday 17 September** to SeneddHealth@senedd.wales, or by post to Health and Social Care Committee, Welsh Parliament, Cardiff, CF99 1SN.

You can find more information about how to share your views at the end of this document, including guidance on providing written evidence, information about the Senedd's two official languages, and details about how we will use the information you provide.

About you

This section of the form asks you some questions about yourself and the capacity in which you are responding to this consultation. This will help us to process and use your information in line with our privacy policy.

Your details		
1. Name:	Sue Farrington	
2. Email address:	RAIRDAuk@gmail.com	
3. Would you like to be added to the Health and Social Care Committee's contacts list in order to receive updates about our work?	Yes No	☒ ☐
You can unsubscribe at any time by emailing SeneddHealth@senedd.wales.		
4. Please tell us in what capacity you are responding to this consultation.		
I am an individual responding in a personal capacity		
I am an individual responding in a professional capacity (please tell us what your job title is)		
I am responding on behalf of an organisation (please tell us which organisation and what your job title is)	Co-Chair, Rare Autoimmune Rheumatic Disease Alliance	
If you are under 13 years old, we will only be able to accept your response if your parent or guardian has confirmed that you can participate. They can do this by sending us an email to SeneddHealth@senedd.wales. **5.** Are you under 13 years old?		
I am under 13 years old	☐	
I am 13 or over	☒	
6. Please choose one of the following options to confirm whether you would prefer that your name is not published alongside your evidence. We will not publish the names of people under the age of 18.		

I am aged 18 or over and I am content for you to publish my name alongside my evidence	☒
I am aged 18 or over and I would prefer that you did not publish my name alongside my evidence	☐
I am under the age of 18	☐
7. Please choose one of the following options to confirm whether you have agreement from any third parties referred to in your evidence that you can share information that may be used to identify them and that they understand that it may be published.	
I confirm that any third party I have referred to in my evidence has agreed that I can share information that may be used to identify them, and that they understand that it may be published.	☒
I do not have the agreement of one or more of the third parties I have referred to in my evidence.	☐
I have not referred to any third parties in my evidence.	☐

Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.
In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

Access to services for long-term chronic conditions, including musculoskeletal conditions

Rare autoimmune rheumatic diseases (RAIRDs) like vasculitis, scleroderma, lupus or Sjögren's syndrome are often categorized as musculoskeletal conditions. Whilst they have some similarities with more common MSK conditions like arthritis, they have a much higher mortality and morbidity rate**.** Based on research using healthcare data in England which indicates there are 174,000 people who have ever been hospitalised with a RAIRD in that country, we believe there are around 9,000 people with these diseases in Wales.

These conditions are characterised by the body's own immune system attacking healthy tissues, often in multiple organs throughout the body simultaneously. The impacts of these conditions on a patient can be severely life-limiting and life-threatening. Rheumatology is often the speciality which leads on care for these diseases, although their severity and complexity often means other specialities need to be involved in their care.

Despite the severity of RAIRDs, there are major issues with care for these diseases in Wales compared to the rest of the UK. For example, these are comments made by patients in response to a survey we carried out in June 2021:

> *"I feel the Welsh NHS has abandoned me, I'm fortunate I can pay to access treatment and consultation in England, but there is a desperate need for a centre in Wales to treat patients like myself with specialist care."*
> *Sjögren's syndrome patient*
>
> *"Patients with chronic ill health are being failed in Wales. There is no support, no monitoring, no bloods taken, no medication. I worked hard in my career. For the past eleven years I have become incapacitated by my illness. I have lost my career and am now unable to afford private care."*
> *Lupus, vasculitis, and antiphospholipid syndrome patient*
>
> *"I was under the care of a health board outside of where I lived initially and as it was a specialist centre I had very good care. However, I've been repatriated to my local health board and since then the care I've had has been awful, in fact it's been non-existent."*
> *Lupus and Sjögren's syndrome patient*
>
> *"I have felt totally abandoned for the last 5 years since being diagnosed."*
> *Vasculitis patient*

> *"Having to fight the health board for minimal contact."*
> *Undifferentiated connective tissue disease patient*
> *"I'm often waiting for months despite appealing for help."*
> *Sjögren's syndrome*

In 2018, we carried out a UK-wide survey with 2,000 respondents. Fresh analysis of that survey has found that patients in Wales, compared to the rest of the UK, were more likely to:

- Wait longer than 6 months to see a consultant when waiting for diagnosis.
- Resort to seeking care from a private provider.

And were less likely to:

- Have confidence in their GP's knowledge of their condition.
- Have a coordinated plan in place for their care.
- Have a specialist nurse involved in their care. For those respondents in Wales with nurses involved in their care, they found these nurses harder to contact than respondents in England.

With significant differences between the care reported in England and Wales before the pandemic, we believe improving care for RAIRDs in Wales needs to be a priority for the Welsh Government. We therefore hope that the Committee will include a focus on RAIRDs in its inquiry looking at MSK conditions. These conditions have been neglected in Wales and this must be remedied.

We have suggested particular reasons for the poor experience of patients in Wales below that the Committee may wish to look into below.

There are no formally commissioned specialised centres for these conditions in Wales

There is a concerning lack of access to specialist care in Wales for these conditions. Other UK nations acknowledge the need to invest in specialised services for these patients, which offer more than all local rheumatology departments can offer. In Wales however, whilst some clinicians and departments are informally recognised having expertise in caring for these conditions, there are no formally commissioned specialised services for these conditions in Wales. We think this is a major reason why the average patient in Wales reports worse care than in the rest of the UK.

In our survey of patients in Wales in 2021, we found that 80% of patients had ever accessed care for their condition at their local hospital's rheumatology department. Only 11% reported accessing care at a more specialised centre in Wales which they had been referred onto by another doctor. 29% reported accessing care in a specialised centre in England, although comments indicate that many did so privately. This is further evidence that there is a need for easier access to specialist care for these conditions in Wales.

Local care is not always best when that care is insufficient. Our 2021 survey shows that patients are very much prepared to travel further, as the establishment of a specialised service or services would imply. 80% of patients said they would be willing to travel further, with 46% saying they would be willing to travel 2 hours more or longer. Only 2% said they would not travel any further, 9% said they already accessed care at the most specialised centre they could. 9% were unsure.

The *amount* of travel matters to patients, but discussion is often focused on *distance*. Patients tell us they would far rather travel once, further, to a specialist centre which resolves their issues, rather than having to make repeated visits to their GP or local hospital where issues are left potentially unresolved after a single visit.

> *"I would like access to specialist doctors and nurses who fully understand the condition, even if it means travelling to specialist hospitals in England. I often feel like I get a lot less when I talk to other patients having treatment in specialist hospitals."*
> *Scleroderma patient*

Current systems do not support shared care or networks involving local and specialised centres sharing expertise.

Whilst all rheumatologists have some knowledge of RAIRDs, other nations in the UK, particularly England, have recognised that not all rheumatologists have the same knowledge, experience, and confidence in treating and caring for people with these diseases, or access to the technical and organisational resources to allow them to deliver quality care. It is for this reason that

England has commissioned specialised centres for these diseases and that Scotland is working to establish a National Managed Network for Vasculitis.

Overall, 52% of Welsh patients with a RAIRD cared for by a rheumatologist said they had confidence in their understanding of their disease. The confidence in rheumatologists was highest among those patients who had their care coordinated by some kind of specialised centre in Wales or England at 73%.

The proportion of patients in 2018 that had a coordinated care plan in place was low across the UK. However, it is substantially lower in Wales at 27% compared to 40% across the UK. This further shows the need to commission specialised centres and networks and properly resource departments, so they are capable of coordinating care.

The above evidence supports the commissioning of at least one specialised centre for the care of these diseases. These centres should work in a network, where the specialised 'hub' helps local 'spokes' to ensure everyone is delivering good care. Specialist centres, and the clinicians with a particular interest in these conditions who lead them, will have more experience and knowledge of rare autoimmune rheumatic diseases than clinicians in local centres.

The aim is a system where specialised centres offer excellent care, and support local centres to improve the care they offer. Local centres should be able to seek advice from, as well as share care with, specialised centres. The Getting It Right First Time (GIRFT is part of an aligned set of programmes within NHS England and NHS Improvement) national specialty report for Rheumatology examines best practice for establishing these networks and Wales can now learn from what has worked, and what has not, in England. These networks do require investment, sufficient administrative support, and time in clinicians' job plans to work effectively.

We are concerned that the current Individual Patient Funding Request system in Wales is the antithesis of this system and actively discourages local departments from seeking specialised support, including when this would actually be cost-saving by preventing disease progression.

Multi-speciality care and clinics are rare in Wales

The importance of multidisciplinary team input, and for well-coordinated care across different specialties is noted for inflammatory conditions. For RAIRDs, which may involve multiple organ systems, this is particularly important.

In RAIRDA's 2018 survey, only 9% of patients living in Wales reported they had ever accessed care at a clinic with doctors from multiple different specialties. This compared to a, still low, 17% across the rest of the UK. This is despite 93% of UK survey respondents reporting seeing clinicians from multiple specialties.

Patients commented that the multi-system nature of these conditions was not appreciated by healthcare professionals – again, ensuring better cross-speciality care and specialist expertise is important.

> *"I lost confidence in the care here in Wales after being unable to see a specialist for months on end while I was really ill, and then being misdiagnosed and told I had to wait even longer for a skin specialist (I did not need a skin specialist, I needed a kidney specialist). That episode led to some permanent damage."*
>
> *Lupus patient*

This should make sure this is not just understood, but that care is delivered in a way which respects this. Formally commissioning a specialised centre or centres for RAIRDs which have access to specific specialties, as occurs in England, will at least support better cross-speciality access in these centres.

Impact of the Covid-19 pandemic

In June 2021 we asked patients what impact the pandemic had on the care they receive for their condition and the impact this had on their ability to manage their condition. 41% said the pandemic had a major negative impact, 29% said the pandemic had a minor negative impact.

Across the UK, we're concerned there is now a substantial number of relatively stable patients who have not had their condition monitored or checked in a long time. This is on top of the fact that some very ill patients seemed to have issues accessing care.

> *"I went privately as I didn't know who to contact during a flare. He explained it will be due to COVID that the rheumatology nurses don't answer the phone, or reply to messages left."*
>
> *Lupus patient*

> *"Getting access to phone calls with a specialist nurse or a rheumatologist has been incredibly difficult through the pandemic."*
> *Undifferentiated connective tissue disease patient*

The ability of patients to get assistance early can help prevent issues escalating and prevent patients requiring more care from the health service.

We know that long diagnostic journeys cause serious distress and heighten the impact these conditions have on patients' mental health, but there is also evidence they increase the costs on health services in the long run as disease is left uncontrolled, increasing the chance that it is able to cause serious damage to organs.

> *"My consultant thinks I would have been diagnosed sooner had it not been for the impact of the pandemic on services. As a result, I was very ill when I was diagnosed, which has implications going forward."*
> *Vasculitis patient*

The longer waiting times caused by the pandemic will increase the time taken to diagnose patients, as well as making caring for existing patients difficult. New ways of working, as well as increasing the capacity of rheumatology departments, will be important to deal with this.

The health and social care workforce, including organisational culture and staff wellbeing

Rheumatology workforce crisis

Many rheumatology units are facing significant workforce challenges. It has become increasingly apparent that there is an imbalance between capacity and demand in many areas. Evidence from patients, detailed in this response, show that shortages of staff are directly reflected in the quality of care patients receive. We support the recommendations of the recent report '**Rheumatology workforce: a crisis in numbers**' by BSR. Whilst there are issues across the UK, BSR's report contains significant evidence of issues in Wales. Whilst there are issues with the rheumatology workforce across the UK, we do think these issues are particularly acute in Wales.

For example, in 2018, 24% of RAIRD patients in the rest of the UK waited over 6 months to see a specialist. In Wales the figure was 35%. This comes on top of evidence cited earlier in this report of overstretched services, such as higher proportions of patients seeking private care and higher proportions reporting a lack of a coordinated care plan.

Comments we received from patients in 2021 provide further evidence of the extent of the crisis:

"My rheumatologist left the health board over 2 years ago and I have been left in limbo with care."
Lupus patient

"The rheumatology department is vastly understaffed and waiting list for clinics are long. Therefore, conditions deteriorate and end up needing more intensive intervention making the rheumatologists job much more difficult and burdening the waiting list more."
Lupus and Sjögren's Syndrome patient

"Rarely get to see anyone. Not unusual for 2-3 years between appointments. GPs really don't understand the condition."
Undifferentiated connective tissue disease patient

"I have had to access specialist care myself in England as the local rheumatology hospital dept cannot give me appointments, I'm often waiting for months despite appealing for help."
Sjögren's syndrome patient

The above evidence highlights the numerous challenges that rheumatology units face including an overstretched workforce and rising demand for services. When combined with the fact patients struggle to get transferred to another health board if their own health board is over capacity, accessing care can become impossible.

We would hope that the evidence presented in the **British Society for Rheumatology's recent workforce report**, alongside evidence from patients, detailed in this response, makes clear there is now an urgent need for action to support the rheumatology workforce through recruitment, training, and new ways of working. We hope the Committee will make sure the Welsh Government takes the necessary action in this area.

Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- ***a)*** *health services;*
- b) *social care and carers;*
- c) *COVID recovery?*

You can comment on as many or few of the issues as you want.
In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

Actions for non-genetic rare diseases

We think rare disease policy is in need of further scrutiny in Wales by the Committee. We are concerned that recommendations made in this area have not been implemented or are so vague they do not result in improvements for patients.

We have yet to see the Welsh Government implementing specific actions relevant to non-genetic rare diseases and we were concerned the draft MSK framework recently consulted on in Wales would not have any positive impact on the awareness of rare diseases or the outcomes from rare diseases in this clinical area. We are particularly disappointed this framework only referenced the now out-of-date Rare Disease Strategy.

Our key criticisms of the, now obsolete, UK Rare Disease Strategy were:

- Rare autoimmune rheumatic diseases have no simple genetic link. This means that significant amounts of the strategy, referring to genomic testing are irrelevant for non-genetic rare autoimmune rheumatic diseases.
- The lack of measurable outcomes has meant it is impossible to say whether the strategy, or national action plans, have improved outcomes for people with rare diseases, particularly for those where diseases have no simple genetic link.

The new UK-wide Rare Disease Framework, which all nations must develop action plans to meet, makes a welcome change in making explicit the need to improve outcomes for people with non-genetic rare diseases. We hope the Welsh Government's rare disease action plan will contain specific, measurable, goals to improve care for people with non-genetic rare diseases. As the Welsh Government is currently developing its new action plan, now is an ideal time for the Committee to ensure that the lessons from the Rare Disease Strategy are learnt.

We were disappointed that the recent Welsh MSK Framework referred to the old Rare Disease Strategy and did not contain any specific or measurable goals for health boards. Instead, its recommendation relevant for rare diseases was a tokenistic reference to the need for health boards to adhere to the Rare Disease Strategy. This Strategy is so top-level and vague that this recommendation will not result in specific actions by health boards which support people with rare diseases like RAIRDs.

When there are clear and specific issues for rare diseases in a certain clinical area, such as RAIRDs, we need frameworks like the forthcoming MSK Framework to give health boards specific actions on them. Only then will rare disease policy actually result in actions which support people with rare diseases.

Wales Rare Disease Strategy Implementation Plan (2017, page 15, action 4 and 5) recommended the following key actions: *Work with health boards as providers and NHS England to:* ● *develop and agree service specifications;* ● *develop an agreed process for monitoring services against specification; implement and monitor services against service specification including outcome and audit monitoring;* ● *consider possibility of establishing hub and spoke service delivery* *Health boards to ensure the individual care plan considers all aspects of health and social care needs, including access to; medical devices or treatment, benefits advice where appropriate, and in the case of children transition arrangements;* We would support the implementation of the above recommendations, however so far, we have not heard of any developments to do that with RAIRDs, despite both Scotland making steps in this direction, and England commissioning specialised services according to specifications since 2013. This is another reason we would welcome the Committee scrutinising rare disease policy in Wales.
b) Social care and carers
c) COVID recovery

Question 3: Any other issues

Q3. Are there any other issues you wish to draw to the Committee's attention?

Submitting evidence

Guidance on providing written evidence

If you have any questions about this consultation or providing written evidence, please contact us at **SeneddHealth@senedd.wales** or on 0300 200 6565. You may also wish to read the advice on **"Getting involved with committees"**, which explains how to prepare and submit evidence to Senedd committees.

Official languages

The Senedd has two official languages, Welsh and English. In line with the **Senedd's Official Languages Scheme**, we request that you submit your response in both languages if you are able to do so. If your response is not submitted bilingually, we will publish in the language submitted, stating that it has been received in that language only. We expect other organisations to implement their own standards or schemes and to comply with their statutory obligation.

How we will use your information

General information regarding consultations, which you should consider carefully before submitting a response to the Committee, is available in our **privacy notice**.

How to submit your response

We prefer to receive evidence digitally (for both practical and sustainability purposes). Please send an electronic copy of your form to **SeneddHealth@senedd.wales**.

If you cannot provide evidence digitally , you can send a copy to:

Health and Social Care Committee
Welsh Parliament
Cardiff
CF99 1SN

Responses should be submitted no later than **16.00 on 17 September 2021**.